

What a difference a break makes: a vision for the future of short breaks for unpaid carers in Wales

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WHAT A DIFFERENCE A BREAK MAKES: A VISION FOR THE FUTURE OF SHORT BREAKS FOR UNPAID CARERS IN WALES



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WHAT A DIFFERENCE A BREAK MAKES: A VISION FOR THE FUTURE OF SHORT BREAKS FOR UNPAID CARERS IN WALES

Introduction

This report sets out a vision for creative short breaks that are coproduced with unpaid carers and the people they support and reflect the personal outcomes they wish to achieve. Starting with a definition of short breaks, it goes on to identify twelve key principles to inform future short break options and what they might look like in practice, drawing on examples from Wales and other regions of the UK. The report also outlines where there are knowledge gaps and challenges in implementing the principles into practice. Four priority areas for Welsh Government development and investment are identified:

- 1. Regional Short Breaks Statements.**
- 2. A National Short Breaks Information and Guidance Hub.**
- 3. A National Respite Initiative for Wales.**
- 4. A National Short Breaks Fund.**

The priority areas are rooted in the twelve key principles and informed by our understanding of the international evidence base. Sustained investment is essential to realising the policy objective to *support a life alongside* caring.

Context

Wales has the highest percentage of unpaid carers in the UK and the highest proportion of older unpaid carers providing more than fifty hours care each week (Social Care Institute for Excellence [SCIE], 2018). The challenges and satisfactions unpaid carers in Wales experience when looking after people with complex care and support needs are well documented (Burrows et al., 2021; SCIE, 2021). A break from caring can make a positive difference to unpaid carers' health and wellbeing and their ability and willingness to continue in the caring role (Roberts and Struckmeyer, 2018; Carers UK 2021), especially when a break is combined with other types of help and support (Brimblecombe et al., 2018). Unpaid carers consistently rate better access to breaks as their key priority and this is evidenced in a recent report *Breaks or Breakdown* (Carers UK, 2021). The Welsh Government recognise the importance of regular and appropriate breaks from caring (National Assembly for Wales, 2019) and *supporting a life alongside* caring is one of four national priorities for carers living in Wales (Strategy for Unpaid Carers, Welsh Government, 2021).

Despite the longstanding policy commitment to supporting unpaid carers in Wales and the other UK regions, unpaid carers continue to report difficulties in accessing breaks, a lack of flexible break options and limited opportunities to take a break together (Carers Trust Wales, 2018; National Assembly for Wales, 2019; Carers UK, 2021). Unpaid carers feel that their break needs are not sufficiently explored during a carer assessment (Carers UK, 2019). They highlight difficulties in sourcing information about breaks and challenges in planning personalised breaks that reflect their unique circumstances (Shared Care Scotland, 2012; Carers UK, 2021). There is a mismatch between traditional 'one size fits all' options and the lives of many unpaid carers and the people they support. Consequently, considerable resource is spent on provision that does not always help people to achieve desired wellbeing outcomes (O'Shea *et al.*, 2020).

Evidence submitted to the National Assembly for Wales inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to unpaid carers suggests that the commissioning of breaks focuses on price rather than on quality of break options (National Assembly for Wales, 2019). The need for more creative, bespoke approaches to commissioning and delivering breaks is widely acknowledged. There is a commitment to meaningfully involve unpaid carers and the people they support from across Wales in the design and development of breaks and to engage with key sectors, including hospitality and tourism, to explore break options (National Assembly for Wales, 2019). Research highlights an emerging new role for commissioners as facilitators of change (Seddon *et al.*, 2021).

The COVID pandemic has placed significant financial, practical and emotional challenges on unpaid carers across Wales

(Burrows *et al.*, 2021) and has necessitated a rapid transformation of the ways carers and the people they support are helped to take a short break. Creative approaches to breaks have developed during this time, some of which are highlighted in this report. As Wales moves forward, it is timely to think about the direction of travel, knowing that there is likely to be renewed and increased demand for short breaks whilst at the same time concerns about re-engaging with break opportunities available in local communities. This report highlights options for flexible, creative short breaks that meaningfully support and effectively sustain the diversity of caring relationships across Wales.

Respite and short breaks: what do we mean?

Many terms are used to describe breaks from caring, including respite, short breaks, restorative, replacement and relief care. The most common ones are respite care and short breaks. **Respite** is defined as a break from something that is unpleasant. It usually involves someone with complex care and support needs being supported in settings outside the home and separated from their carer (though in-home respite is sometimes provided). Whilst traditional forms of respite can be beneficial for some families and indeed, they have their place, respite is an increasingly contested term that is off-putting to unpaid carers (Rochira, 2018; SCIE, 2018). The concept of a **short break**, as a means of supporting families and sustaining caring relationships, is more acceptable to unpaid carers and the people they support (Bliss, 2006; Rochira, 2018). Short breaks are associated with a shift in focus from supporting unpaid carers in their caring role to improving quality of life for *both* the unpaid carer and the person they support, potentially including a break taken *together*. A short break aligns with the policy commitment

to develop personalised approaches to supporting people to achieve those things that matter most to them. A short break can mean different things to different people (Carers UK, 2021). It is important to recognise the crucial role short breaks play in enabling unpaid carers to both cope and thrive day to day. In many cases, short breaks provide unpaid carers with the opportunity to do very basic things like attend medical appointments, get a haircut and socialise with friends. These activities, and the short breaks that allow them to happen, can and must form part of unpaid carers' usual routine and should not be considered as an intervention to avoid crisis or something atypical to usual routine activities.

The position statement from Shared Care Scotland (2017) provides a helpful reference point when thinking about the defining characteristics of a short break:

A short break is any form of service or assistance, which enables the carer(s) to have sufficient and regular periods away from their caring routines or responsibilities, with the purpose to support the caring relationship and promote the health and well-being of the carer, the supported person and other family members affected by the caring situation.

Examples may be found using the following link: <https://www.sharedcarescotland.org.uk/resources/briefings/short-breaks-definition/>

Short break is used in this report to reflect what is now considered a more positive and acceptable term. It is used in the broadest sense, as this helps to support choice and encourage people to think about creative break options that reflect the unique nature of caring relationships. In response to the findings of this review, and through conversations with unpaid carers, practitioners and commissioners, the

following working definition of short break is suggested as it is concise, coproduced, inclusive and outcome-focused:

*Any break, which **strengthens** and/or **sustains** informal caring relationships and **enhances** the wellbeing of carers and the people they support.*

This may be achieved through a service, an activity or an item.

During a review of respite, commissioned by the West Wales Care Partnership (Andrews, 2019), unpaid carers reflected on the need for plain language to describe breaks from caring. Some of their suggestions are captured here:



Evidence underpinning this report

This report is informed by:

- National research by Carers Trust Wales to understand breaks provision from the perspectives of unpaid carers, providers and commissioners (Carers Trust Wales, 2018).
- Academic and practice expertise, that includes findings from an action research project (Andrews et al., 2015), the South and West Wales Stay-Well Network activity (Thomas et al., 2019), a regional review of respite commissioned by the West Wales Care Partnership (Andrews, 2019), and a scoping review of the international evidence on respite and short breaks (Seddon et al., 2021).
- Two pan-Wales webinars, hosted by Carers Trust Wales, and one-to-one discussions with stakeholders.

Webinar one engaged delegates from the statutory and third sectors, including individuals in strategic and operational roles, as well as unpaid carers. The webinar explored:

- Key principles to inform short break options going forward.
- Challenges and opportunities of applying these principles in practice.
- Examples of existing good practice and creative break options.

A set of draft principles were developed and sent to delegates in advance. These were informed by the scoping review (Seddon et al., 2021), the practice development review (Andrews, 2019) and pan-Wales research undertaken by the Carers Trust Wales in 2018. The draft principles, and associated descriptors, provided a focal point for discussions and break-out group activities to agree the set of 12 key principles presented in this report. Following the first webinar, one-to-one meetings were held with stakeholders from across the UK to explore ways to embed the key principles into practice and to identify models to underpin the future delivery of short breaks. Webinar Two was convened to:

- Present the final principles.
- Present and consider the four priority areas for investment.

A vision for the future of short breaks for unpaid carers in Wales: twelve key principles

Table One summarises the twelve key principles that were coproduced with stakeholders. These principles capture the vision for short breaks for unpaid carers, of all ages, in Wales and the people they support. They reflect the Welsh Government's commitment to recognising, valuing and supporting unpaid carers of all ages to live well and achieve personal wellbeing outcomes, as described in the Strategy for Unpaid Carers (Welsh Government, 2021).

Aligned with the Welsh Government's four national priorities for unpaid carers, the principles provide a focus for future commissioning and practice development activities.

Table One: Twelve key principles for short breaks

Principle	Descriptor
See individuals and focus on what personal outcomes matter to carers and the people they support	<p>Start with a 'what matters' conversation so that:</p> <ul style="list-style-type: none"> • Break outcomes that matter most to people are given meaningful consideration • The exploration of break options with people is mindful of the active offer, of language, culture and diversity
Build on strengths in supporting and sustaining caring relationships	<p>As well as identifying difficulties in caring, explore:</p> <ul style="list-style-type: none"> • Satisfactions in caring and positive ways of coping • Ways a break can help to support these, including breaks taken together as well as apart
Be sensitive to caring relationships and work towards making breaks a positive experience for everyone	<p>As far as possible, ensure:</p> <ul style="list-style-type: none"> • The interdependent wellbeing of carers and the people they support • Carers do not feel guilty and the people they support do not feel a burden
Provide accessible and timely information about break options	<p>Provide information:</p> <ul style="list-style-type: none"> • On a variety of break options, including breaks taken together and breaks taken apart, scheduled breaks and breaks to cover emergency situations • At a time when it is needed, in formats that are accessible and engaging , and, for the youngest carers, are age appropriate
Offer supported choice of breaks and help with decision-making	<ul style="list-style-type: none"> • Offer relational support to help people think through their break options – do not give them a list
Provide personalised, flexible and responsive break options, that reflect the diversity of the carer population	<ul style="list-style-type: none"> • Ensure people have access to timely, personalised break options, including breaks that can support them to engage in paid employment, education/training and leisure should they wish • Ensure break options recognise important factors relating to diversity and inclusion, for example, age, disability, language and culture • Be responsive to changing needs and preferences

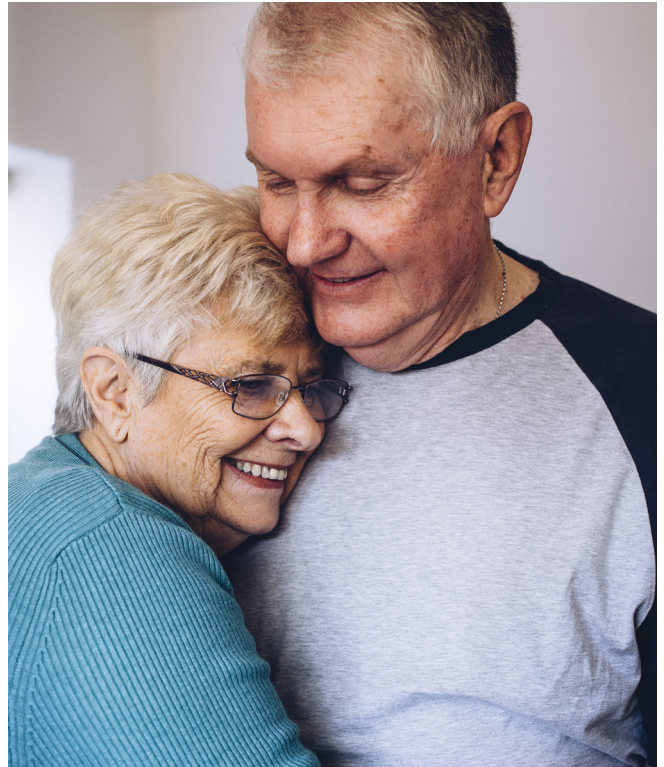
Identify and promote creative approaches to commissioning and other statutory funded and no cost breaks options	<p>Think 'outside the box' about:</p> <ul style="list-style-type: none"> • Alternative ways to commission and fund breaks, for example, through the development of social enterprises, individual and pooled Direct Payments as well as no cost options • The challenges and opportunities associated with implementing these into practice
Build links with key sectors that relate to everyday life not just social care and health	<ul style="list-style-type: none"> • Design breaks through collaborative working, for example, with hospitality, tourism, arts, leisure and education • Strengthen collaboration with health services on the provision of short breaks for people with complex needs and their carers • Work with health services to proactively identify carers whose break opportunities are most likely to be limited because of the complex nature of care they provide
Promote and support creative break options in the local community and communities of interest	<ul style="list-style-type: none"> • Support the development of diverse local community breaks for people, including informal support and micro-enterprises • Embed both creativity and safety in break options moving forward from the pandemic, including in-person and online options
Nurture the development of peer support	<ul style="list-style-type: none"> • Ensure opportunities for carers to access/benefit from peer support • Explore ways to facilitate this, including collective break options, delivered face-to-face or online
Ensure quality of break options with a particular focus on what matters to carers and the people they support	<p>Develop approaches to quality assurance that are:</p> <ul style="list-style-type: none"> • Meaningful • Support learning and further development
Capture outcomes arising from a break for carers and the people they support	<ul style="list-style-type: none"> • Identify ways to effectively capture break outcomes - both planned and serendipitous outcomes • Ensure this information informs future policy and practice development

PRINCIPLE 1:

SEE INDIVIDUALS AND FOCUS ON WHAT PERSONAL OUTCOMES MATTER TO CARERS AND THE PEOPLE THEY SUPPORT

What this principle looks like in practice:

- The unique nature of caring relationships, individuals' lived experiences, break needs and break preferences, are acknowledged and are captured in what matters conversations.
- When exploring break needs and break options, people are supported to think 'outside the box' and to develop the confidence and self-awareness to make meaningful and effective choices.
- When exploring break options, people are mindful of language, culture and diversity.
- The break outcomes that matter most to people are given meaningful consideration.



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The really important part of those human needs is being noticed, loved and accepted as a human being and not a human doing. And I think what I've caught already from what people are saying is... you become a tick... something to be dealt with instead of a person with real needs.



Quote from carer:

Illustrative examples from practice:

Blue MacAskill, a Powys based artist and creative practitioner, has linked with **Credu** to use arts to facilitate creative conversations about caring relationships, break needs and break preferences. Alongside this work, **Credu** through their **Creative Respite Project**, are seeking to develop coproductive relationships between carers, practitioners, commissioners and providers, to create bespoke, meaningful breaks that reflect what matters to individuals: <https://www.carers.cymru/creduprojects>

Shared Care Scotland collate and publish short breaks stories that are written in carers' own words. Stories provide a reference point to inspire creative conversations about bespoke short breaks and to highlight the transformational impact these breaks can have. This useful resource illustrates the diversity of break options: <https://www.sharedcarescotland.org.uk/learning-exchange/short-break-short-stories/>

Shared Care Scotland have produced an **Inspiring Breaks Toolkit** to inspire new thinking about breaks that meet the outcomes mattering most to people: <https://www.sharedcarescotland.org.uk/resources/tools/inspiring-breaks-toolkit/>

Key challenges to be explored and overcome:

- Empowering people to articulate what matters to them and make meaningful and effective choices.
- Traditional ideas, held by professionals and by carers, about what a break involves, how and where it is provided.
- Reticence to think 'outside the box' for fear of raising peoples' expectations.
- Finding ways to meet the commitment, outlined in the SSWBA, to give carers and those they support greater choice, voice and control.
- Tick-box approaches to assessment.
- Service matching practice, which sees carers and those they support aligned with a set menu of breaks provision.

PRINCIPLE 2:

BUILD ON STRENGTHS IN SUPPORTING AND SUSTAINING CARING RELATIONSHIPS

What this principle looks like in practice:

- The intrinsic links between carers and the person they support are fully recognised.
- As well as identifying difficulties in caring, we explore satisfactions in caring and positive ways of coping and consider how a break can help to support these.
- We identify ways to build on peoples' strengths and resources.
- We recognise that caring relationships can be reciprocal in nature.
- We recognise that carers may require a break from the caring role but not from the person they care for - people are supported to take a break *together* if they wish.
- Breaks are recognised as an essential preventive (not reactionary) measure.



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“

I have got closer to dad... certain barriers, if they were there at all, have just fallen away... I have found that it has allowed me to see a more in-depth person behind what I thought was there, so we have become much closer.

Quote from carer:

”

Illustrative examples from practice:

To help people prepare for a Carer's Needs Assessment, **Swansea Council** provide a pre-assessment questionnaire for carers (based on research) to reflect on their caring role. It is intended to help them to consider the satisfactions of caring and helpful ways of managing caring as well as the difficulties, which can then be used as a focus for conversation with a social worker or other person: <https://www.swansea.gov.uk/CarersNeedsAssessment>

Dementia Adventure help people across the UK to get outdoors and to connect with nature, with themselves and with their community. They offer supported holidays for people living with dementia and their families, so breaks can be taken together. It builds on the strengths of caring relationships through mutual support and enjoyment: <https://dementiaadventure.co.uk/what-we-do/our-holidays/>

Key challenges to be explored and overcome:

- The term *respite* and its association with the alleviation of things that are unpleasant and burdensome.
- Traditional ideas of breaks involving a *service* and *separation*.
- Reactive rather than preventive approaches to supporting people with complex care needs and their carers.
- Assumptions about carer willingness and ability to care.
- Assumptions about how carers should occupy their break time.

PRINCIPLE 3:

BE SENSITIVE TO CARING RELATIONSHIPS AND WORK TOWARDS MAKING BREAKS A POSITIVE EXPERIENCE FOR EVERYONE

What this principle looks like in practice:

- The interdependent wellbeing of carers and the people they support is recognised.
- Carers are supported to recognise their need for a break and do not feel guilty about this. The people they support do not feel a burden.
- It is widely recognised that impactful breaks are characterised by positive experiences *both* for the carer and those they support.
- The history of the caring relationship is understood, including what breaks might have worked well/not worked well previously.



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“

I know that we need a break, but I always feel guilty... once we've gone and everything's settled and I know he's fine, I enjoy it, but the initial leaving, going, actually doing something. I find that really difficult.

Quote from carer:

”

Illustrative examples from practice:

TRIO is a unique care service for anyone living in North Wales who is living with dementia. People are paired up with a TRIO service companion based on similar interests, their personalities and what they enjoy doing most. The companion will then support the people engaging with the service to live their lives to the full: <http://psspeople.com/help-for-professionals/social-care/trio>

The Touch Trust offer inclusive movement-based arts experiences for adults and children with a variety of multisensory needs, learning disabilities and ASD. A person-centred approach celebrates guests' individuality: <https://www.touchtrust.co.uk/>

The Life Changes Trust Get Outdoors Programme provides opportunities for people living with dementia and their carers to enjoy the benefits of spending time outside together, for example, reliving sporting memories, making new memories and engaging with wildlife. A recent evaluation of this programme, 'Outside the Box,' highlights clear benefits for people living with dementia and their carers: <https://www.lifechangestrust.org.uk/sites/default/files/publication/files/OTB%20Final%20Evaluation%20Report.pdf>

Key challenges to be explored and overcome:

- People have time and space to do the things that matter to them, give their life meaning or promote their wellbeing.
- Break activities should provide meaningful engagement for people with complex care and support needs.
- Traditional approaches to risk and risk assessment are not always helpful.
- Distinctions between carers and cared for persons can present obstacles.
- Many carers are reluctant to accept support that is for them.
- People with care and support needs may resent their carer having a break.

PRINCIPLE 4:

PROVIDE ACCESSIBLE AND TIMELY INFORMATION ABOUT BREAK OPTIONS

What this principle looks like in practice:

- Information is provided on a variety of break options, including breaks taken together and breaks taken apart, scheduled breaks and breaks to cover emergency situations.
- Information is available in formats that are accessible, engaging and timely.
- There is a single point of contact for carers needing support to arrange a break.
- There is a national Information and Guidance Hub of break options accessible to carers, people with care needs, practitioners, commissioners and providers that includes an agreed set of information and signposts to community-based initiatives.
- Carers have access to a curated resource.



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“

*How do you get hold of it, this information about respite?
What do you do to get into a position where you can
actually access resources?*

Quote from carer:

”

Illustrative examples from practice:

In 2019 the **West Wales Care Partnership** undertook a review of respite care, with a shift in focus towards more creative short breaks. They explored a wide range of traditional and innovative break options and are continuing to explore and develop these: https://drive.google.com/file/d/1ktxb0A2GM2_ggalkDFgFMuZOERttUcxV/view?usp=sharing

Shared Care Scotland hosts a **Short Breaks Information Bureau** supported by money from the Scottish Government. It does not recommend a particular service, nor does it act as a booking agent. It is available online and via telephone. An example of breaks for children and young people can be found here: <https://www.sharedcarescotland.org.uk/directory/4629/falkirk-tayavalla-short-breaks/>

Shared Care Scotland has published a good practice guide to developing a short break bureau: <https://www.sharedcarescotland.org.uk/publications/good-practice-guide-developing-short-break-bureau/>

Key challenges to be explored and overcome:

- Some people do not identify as carers.
- Support to help people understand potential break options and how these might help them in their circumstances. An online resource needs to be very user friendly, and a lot of people will want to talk through their options.
- The availability of timely and appropriate information, that captures the diversity of break options for people and harnesses the potential to think creatively to identify personalised break options.
- Keeping online information up to date.
- Capturing local opportunities for taking a break, for example, joining a choir or a knitting club, may be challenging.
- An Information and Guidance Hub would need to develop strong links with a wide range of organisations across Wales, not just organisations with a health or social care remit.

PRINCIPLE 5:

OFFER SUPPORTED CHOICE OF BREAKS AND HELP WITH DECISION-MAKING

What this principle looks like in practice:

- Choice on its own can be stressful. Supported choice can be helpful.
- To support choice we need *relationships*, not processes, *approaches*, not tools.
- People are offered impartial relational support to help them think through their break options. An Information and Guidance Hub may help.
- People embedded in the community, with knowledge and expertise (e.g. Community Connectors and Carer Support Workers) provide relevant and timely advice to help carers make sense of the information about short break options.
- People providing relational support have access to a wide knowledge base of short break options as well the listening skills that are required.
- Breaks are negotiated and coproduced with people to reflect *what matters* to them and what is possible.
- The reach of short breaks to carers is extended.



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When your loved one is suddenly diagnosed with a stroke, a heart attack, whatever they've been assessed with, the last thing you've got is a clear head to do some of these things. You could do with a buddy or someone to point the way.



Quote from carer:

Illustrative examples from practice:

Bridging the Gap service, NEWCIS, provide relational support over the phone and in person. They create a reflective space for carers to talk about and think through their short break options: <https://drive.google.com/file/d/13cKQgo40hj1omQEslqmgA8rLK4T8Zbaa/view>

Community Connectors, Pembrokeshire. Carers are assisted to access support groups and activities thanks to what matters conversations with Community Connectors. Without this relational support and encouragement, they would not have the confidence to do so: <https://connectpembrokeshire.org.uk/community-connectors>

Shared Care Scotland Inspiring Breaks Toolkit and Training helps people think through their short break options and there is a training programme for practitioners to help them use the tool: https://www.sharedcarescotland.org.uk/wp-content/uploads/2020/04/SCS_Inspiring_Breaks_toolkit_proof_02.pdf

Key challenges to be explored and overcome:

- People may not find it easy to think about their own needs and outcomes and different ways of fulfilling them. A list of break options can overwhelm them.
- Organisations sometimes undervalue the importance of talking together in their drive to provide information. They need to make time and space for talk, both one to one and in small groups.
- Not everyone wants to talk and for them, there is a place for step-by-step guides that can be accessed online or in print.
- Practitioners must not prioritise what they think is appropriate – facilitate not dictate.
- The perception that carers must go via a local authority to access a break needs to be challenged.

PRINCIPLE 6:

PROVIDE PERSONALISED, FLEXIBLE AND RESPONSIVE BREAK OPTIONS, THAT REFLECT THE DIVERSITY OF THE CARER POPULATION

What this principle looks like in practice:

- People have access to a range of timely, personalised break options that support them to do what matters to them, including breaks that can support them to take time out, engage in paid employment, education/training and leisure if they wish.
- Break options recognise important factors relating to diversity and inclusion, for example, age, disability, language and culture.
- Breaks are flexible and responsive to changing needs and preferences. For example, a preference for breaks taken together for parent carers when their child is young that support engagement in community-based activities and, as they grow older, breaks that may be taken apart.
- Breaks address spikes of need.
- Micro enterprises and micro providers, who can support a diverse range of people to access personalised breaks, are encouraged.



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- The creativity and change evidenced during the COVID 19 pandemic is sustained and opportunities to rebuild Wales, with a focus on citizen wellbeing, are harnessed.



The key to the door should be on the carer's side... but it seems to me that the lock is on social services side... they can sometimes unlock the door, but in general, they try to fit us into or the people we care for into their services, not the other way around.

Quote from carer:



Illustrative examples from practice:

Ty Hafan recognise that breaks should be a positive choice, embrace the importance of building relationships with individual families and deliver bespoke break options: <https://www.tyhafan.org/>

Carers Outreach Service North Wales purchased and adapted two caravans for carers to take short breaks together with the person they support: https://www.carersoutreach.org.uk/time_for_me.html

Clynfyw Care Farm provides an alternative and non-stigmatising approach to short breaks for people with learning disabilities and mental health challenges. It provides care and support within the context of farm life and sustainability, rather than health or social care: <https://www.clynfyw.co.uk/>

Key challenges to be explored and overcome:

- Overcoming traditional approaches to eligibility in social services that often exclude things outside the existing menu of services.
- Assumptions that breaks must happen away from home and involve separation of the carer and the person they support.
- Organisations, professionals and individuals are afraid to try new things.
- Organisations often think and act within their own silos and it can be challenging for them to understand and engage with other organisations and local communities.
- Greater need to focus on the outcomes of short breaks, however they are provided, rather than how they are provided.

PRINCIPLE 7:

IDENTIFY AND PROMOTE CREATIVE APPROACHES TO COMMISSIONING AND OTHER STATUTORY FUNDED AND LOW COST/NO COST BREAKS OPTIONS

What this principle looks like in practice:

- Recognise the importance of breaks and provide sustainable funding.
- Focus on *outcomes* and diverse ways of achieving these including funded and low cost/no cost options utilising a wide range of resources.
- Take a coproduction approach to commissioning working closely with unpaid carers, existing and potential providers.
- Support the flexible use of Direct Payments both individually and via pooled budgets.
- Offer locally managed voucher schemes to enable more flexible and responsive short breaks, as directed by unpaid carers.
- Welsh Government should take a strategic approach to supporting Regional Partnership Boards and local authorities to support short breaks - demonstrated in a Short Breaks Statement.



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- Regional Partnership Boards take a strategic approach to supporting short breaks that is demonstrated in a published Short Breaks Statement.



I said to social services 'I've got money in the pot for Direct Payments. Can I use that to pay for this thing that has cropped up?' and they said 'No, because Direct Payments cannot be used for that.'

Quote from carer:



Illustrative examples from practice:

Flintshire County Council and Bridging the Gap, NEWCIS. Unpaid carers are allocated a 6-month short breaks budget code and spend their budget as and when needed, drawing from a range of provider services. This award-winning service has resulted in more targeted and effective short breaks at no increased cost to the local authority.

Creative use of Direct Payments in North Wales. Chris and Jayne Roberts, a man with dementia and his carer wife, get a break by attending and presenting at dementia conferences. They have a camper van and their local authority provides them a Direct Payment that is used to cover travel expenses.

Equate Land Base is an excellent example of a creative and collaborative approach to generating breaks for parent carers and their children to enjoy horse-riding: <https://www.facebook.com/EquateCIC/posts/2011785692444521>

Shared Care Scotland operates the **Short Breaks Fund** on behalf of the National Carers Organisations and the Scottish Government: <https://www.sharedcarescotland.org.uk/shortbreaksfund/>

Shared Scotland have also published a guide Promoting **Variety – Shaping Markets and Facilitating Choice in Short Breaks**: <https://www.sharedcarescotland.org.uk/wp-content/uploads/2021/02/SCS-Promoting-Variety-2020-WEB-GR-EDIT.pdf>

Key challenges to be explored and overcome:

- Investment and support are needed to help organisations who are used to providing fixed time and task services to enable them to be more agile and flexible in meeting demand.
- Resource allocation panels and financial systems within local authorities may stifle creativity, if focused on existing service options.
- Approaches to risk – concerns about bad things happening can stop good things happening.

PRINCIPLE 8:

BUILD LINKS WITH KEY SECTORS THAT RELATE TO EVERYDAY LIFE NOT JUST SOCIAL CARE AND HEALTH

What this principle looks like in practice:

- Breaks are designed through collaborative working, for example, with hospitality, tourism, arts, leisure, and education.
- For people with complex needs there is strong collaboration with health services to ensure that their needs can be met during a break.
- Regional Partnership Boards promote joined up and multi-sector collaboration linked to a published Short Breaks Statement.
- Welsh Government promote joined up and multi-sector collaboration linked to a published Short Break Statement. This should include reference to funding, commissioning, guidance and policy that relates to or impacts on the delivery of short breaks.
- There are opportunities for businesses to connect with their local communities and realise their corporate social responsibility commitments.



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- Micro enterprises and micro providers offer creative break options.



A new social worker suggested we could go away together and have the care we needed in a hotel – it was a revelation.

Quote from carer:



Illustrative examples from practice:

The Bluestone Resort in Pembrokeshire provides free accommodation for people living with life limiting conditions and their unpaid carers and family members:

<https://www.bluestonewales.com/>

Social Business Wales hosts the Visitor Economy and Tourism online network. Members are keen to extend their support to carers and are engaging with the All-**Wales Forum** and others on this: <https://businesswales.gov.wales/socialbusinesswales/>

During the Summer holidays, the **University of St Andrews** has provided free accommodation to young carers to enable them to have a break from caring in a seaside town: <https://vimeo.com/340219865>

The Holiday Homes Trust provides the chance for families to enjoy a holiday and create cherished lasting memories. They rent out affordable, accessible caravans at a substantial discount, located in UK holiday destinations: <https://www.holidayhomestrust.info/>

Carefree transforms vacant accommodation into breaks for carers and hosts a booking platform where hospitality partners can donate breaks: <https://carefreespace.org/>

The Scottish Government have supported locally approved Respiteability Delivery Partners that are coordinated nationally by **Shared Care Scotland**. Respiteability operates as a social franchise: <https://www.sharedcarescotland.org.uk/respiteability/>

Key challenges to be explored and overcome:

- Tourism and hospitality providers often equate disability with a physical disability and wheelchair access – there needs to be a programme of education to widen their understanding to support carers and people with diverse needs.
- People working in social services often know little about services in other sectors. There is a need to create opportunities for people from different sectors to talk and to think together about how everyone can benefit from creative thinking.
- People with the most complex needs often require a degree of health service provision, but the experience of many carers is that health and social services do not often work well together in funding and organising short breaks.
- Getting sectors other than social care to engage with the short breaks agenda.

PRINCIPLE 9:

PROMOTE AND SUPPORT CREATIVE BREAK OPTIONS IN THE LOCAL COMMUNITY AND COMMUNITIES OF INTEREST

What this principle looks like in practice:

- Breaks are normalised through the cultivation of carer friendly communities where local communities and their citizens recognise break needs.
- It is recognised that a *life* alongside caring does not always equate to a *service* alongside caring.
- The development of diverse local community breaks for people, including informal support and micro-enterprises, are supported and are widely accessible and enjoyed.
- Many community break activities are self-sufficient in terms of governance and funding with minimal reliance on statutory social care provision.
- Creativity and safety are embedded in break options moving forward from the pandemic, including in-person and online options.
- People may be more interested in communities of interest, than their local



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geographic communities. Improved on-line connectivity can support people to connect with others who share their interests.

- The potential contribution of non-commissioned services such as time banking and community volunteering are recognised.



Social services were struggling to find someone to come into our home, so I could go out, but I told them about Jean, who lives up the road – she used to be a nurse and I asked her if she could help, and she could and that was lovely because we know her.

Quote from carer:



Illustrative examples from practice:

Span Arts in Wales is one of a range of community arts organisations who have developed meaningful online community-based activities during the covid pandemic, which includes a virtual choir: <https://span-arts.org.uk/>

DASH is a community-based organisation in Ceredigion that develops activities in the local community: <https://dashceredigion.org.uk/en/home/>

Key challenges to be explored and overcome:

- Local authority commissioners and social workers are not always aware of what is available locally, but in many parts of Wales this is being overcome through investment in Community Connectors and related community capacity building work.
- Other than through Direct Payments, local authorities do not always find it easy to commission localised micro-enterprises, although this is being developed in Flintshire County Council.
- Identifying communities of interest requires people supporting carers to think and research widely. Carers might be able to connect online with people with shared interests anywhere in the world.
- We must learn and build on the good examples of online community activities that have been developed during the pandemic.

PRINCIPLE 10:

NURTURE THE DEVELOPMENT OF PEER SUPPORT

What this principle looks like in practice:

- Carers often benefit from peer support, both in terms of giving and receiving emotional and practical support as well as a stronger collective voice.
- The focus shifts from investing to do things for people to giving them the tools and resources to do things for *themselves* and develop their own networks.
- Local authorities and other organisations engage meaningfully with peer support groups in the coproduction of short break plans and break options.
- Ways to facilitate peer support, including collective break options, delivered face-to-face or online, are maximised.
- Carers in similar circumstances connect with one another to offer reciprocal support such as house swaps and circles of support.
- The importance of a digital offer, and the sustainability of this offer, post pandemic is recognised.



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I have created around us, a group of carers and I'm doing signposting, just in a small, personal way, so one shall tell another and they shall tell their friends, and then they tell another... 'Oh, you should get this and that' and this gives us a voice.



Quote from carer:

Illustrative examples from practice:

Parent carers for people with learning disabilities in Rhondda Cynon Taff have formed the **Grapevine Peer Support Group**. They work closely with their local authority in strategy and service development and avoid the danger of tokenistic participation by ensuring that a collective voice is heard and responded to.

Parent carers in Grangetown Cardiff have formed **CWTCH Together**, a community cooperative, comprising parents, carers and volunteers who provide a play scheme for children with disabilities and offer peer support. It meets on Saturday mornings in a children's play centre which would otherwise be closed at the weekend:

<https://care.wales.coop/case-studies/cwtch-together/>

Parent carers in **Bridgend** like to go away together with their children as a small group to Llangranog where they can provide mutual support.

Matching Houses helps people to build peer connections to retain choice and flexibility through exchanging accommodation/house swaps:

<https://www.matchinghouses.com/>

Key challenges to be explored and overcome:

- It should not be assumed that peer support comes at no cost. It may need initial and ongoing support and funding.
- Local authority commissioning and funding arrangements, which generally focus on individuals, may find the funding of group short breaks, strengthened by peer support a challenge.
- Carers in different circumstances might require different levels of help to nurture and sustain peer support. For example, older carers with limited mobility.

PRINCIPLE 11:

ENSURE QUALITY OF BREAKS PROVISION WITH A PARTICULAR FOCUS ON WHAT MATTERS TO CARERS AND THOSE THEY SUPPORT

What this principle looks like in practice:

- There is strong and effective communication between carers and short break providers – before, during and at the end of any short break.
- Short break providers pay attention to detail and *what matters* to carers and the people they support.
- Approaches to quality assurance are meaningful and support learning and further development such as Experience Based Co-Design and surveys focused on what matters to carers and the people they support.
- Carers and the people they support are involved in establishing key quality indicators for breaks and these indicators inform commissioning decisions.
- A national Short Breaks Information and Guidance Hub may be a helpful platform to collate short break stories that demonstrate impact.



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Because with regards to respite and everything else, if everything's not in place, the attention to detail, your respite is shot. I find, always something missing. There's always something missing....so it's all got to be in place and if it's not in place it means I cannot relax.

Quote from carer:



Illustrative examples from practice:

The **Developing Evidence Enriched Practice (DEEP)** programme in Swansea University has developed an approach to capturing and learning from short stories of experience called '**Magic and Tragic Moments**'. An example of this regarding the experiences in older people's care homes can be found at: <https://www.dewis.wales/ResourceDirectory/ViewResource.aspx?id=4614>

Researchers in the **University of York** and people supported by day services, developed a simple quality assurance survey regarding person centred care called PERCCI, which has 6 questions about the care and support provided and 6 about the carer workers. It can be downloaded at: <https://www.percci.org/>

Key challenges to be explored and overcome:

- Understanding what quality looks like from the perspectives of carers and the people they support.
- Developing measures that are meaningful but not overly long or complicated.
- Encouraging and supporting the development of organisational cultures that are focused on learning (*improving*) rather than ticking boxes (*proving*).
- The lack of consistent approaches to evaluation.
- Translating quality assurance measures into strategic planning.

PRINCIPLE 12:

CAPTURE OUTCOMES ARISING FROM A BREAK FOR CARERS AND THE PEOPLE THEY SUPPORT

What this principle looks like in practice:

- There are effective ways to capture personalised break outcomes – both planned and serendipitous outcomes and this information informs future policy and practice development.
- There is a systematic and outcome focused approach to planning short breaks based on evidence of what works well for carers and the people they support.
- Each Regional Partnership Board publishes a Short Breaks Statement, coproduced with carers, organisations representing them and commissioners, detailing: carer rights; potential break options and intended outcomes.
- A Social Return on Investment Approach might be helpful in exploring the added social value of personalised breaks.
- There is a focus on meaningful outcomes, and these are mapped onto performance frameworks.



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- Innovative approaches to evaluation that capture outcomes are tested out and refined. For example, the Most Significant Change approach.
- Short breaks are underpinned by a robust research evidence base that connects academia, policy and practice.



The wee little breaks. The little things is all it takes. It means a lot; it makes a big difference – the little things like having my hair done. The little things like going to the shop. A flexible plan where I can do the things that I can do. Yes, the little things, like a life of my own.



Quote from carer:

Illustrative examples from practice:

The **Wales Council for Voluntary Action** has been part of the UK wide Inspiring Impact programme, which has been exploring meaningful and outcome focused approaches to evaluation:

<https://wcva.cymru/impact-evaluation/>

<https://www.inspiringimpact.org/>

Shared Care Scotland have developed a **Short Breaks Evaluation Toolkit** to identify, from key perspectives, what works well and why: <https://www.sharedcarescotland.org.uk/resources/tools/evaluation-toolkit/>

Shared Care Scotland host a **Short Breaks Learning Exchange** to share good practice: <https://www.sharedcarescotland.org.uk/learning-exchange/>

Key challenges to be explored and overcome:

- Capturing personal outcomes that are meaningful can be quite challenging and overly complex methods such as the ASCOT tool are generally not practicable in everyday practice, although may work for a research study.
- Balancing the need for metrics and qualitative evidence, including stories, to inform planning and commissioning.
- Ensuring that short breaks are included in the implementation of the Performance and Improvement Framework for Social Services and other strategic initiatives.

RECOMMENDATIONS TO WELSH GOVERNMENT

Having described the key principles to underpin short breaks and the challenges and opportunities these present we make recommendations to the Welsh Government to help people achieve *a life alongside caring*. We identify four priority areas for development (1) and investment (2,3,4):

- 1. Regional Short Breaks Statements that build on and are linked to a Welsh Government Short Breaks Statement.**
- 2. A National Short Breaks Information and Guidance Hub.**
- 3. A National Respite Initiative for Wales.**
- 4. A National Short Breaks Fund.**

Spending on breaks is an essential investment and change is needed if we are to deliver breaks in line with *what matters*. Sustainability is vital; the impetus to embed lasting change and invest in stable and effective partnerships is significant and there is considerable appetite to try new things. There is also clear evidence of demand and unmet need that could be addressed in part by simply improving the reach and sustainability of services already well placed to understand and respond to unpaid carers' individual needs.

Regional Short Breaks Statements

Regional Partnership Boards should each publish a Short Breaks Statement that sets out their vision for short breaks and their plans to realise this in practice. The Short Break Statement should be coproduced with unpaid carers and the people they support, and it should:

- Be outcome focused not service led (hence we *do not* recommend this be called a short breaks *service* statement).
- Be underpinned by a broad definition of short breaks and a commitment to delivering within the 12 guiding principles set out within this report.
- Describe unpaid carers' rights, their opportunities to take a break and sources of information about breaks.
- Highlight the difference a short break can make, setting out clearly the benefits accessing appropriate short breaks can have for unpaid carers and those they support.
- Identify potential partnerships to support the development of creative break options, including partnerships with sectors such as health, arts and leisure, education and lifelong learning, tourism, hospitality and the environment.
- Acknowledge the crucial role unpaid carers play in underpinning the health and social care sector and the economic and wider social benefits of prioritising the provision of short breaks.

The Short Breaks Statement should link to:

- A National Short Breaks Statement, from the Welsh Government, setting out their aspirations for short breaks and their commitment to achieving these in practice.
- The Welsh Government's national priorities for unpaid carers with an explanation of how these will be achieved.
- The wellbeing outcomes described in the National Outcomes Framework with an explanation of how these will be achieved.
- The national Performance and Improvement Framework for Social Services.
- The 12 principles for short breaks outlined in this report with an explanation of how these principles will be achieved in practice.
- The Wales Carers Charter.

The Welsh Government should specify minimum information requirements to promote consistency across the regions and minimise variation in statement content and quality. Regional Partnership Boards should be accountable for the implementation of their Short Breaks Statement and should report the progress on achieving their vision for short breaks on an annual basis. This information should be shared with the Ministerial Advisory Group for Carers alongside information relating to Welsh Government's progress in achieving against the National Short Breaks Statement.

In Scotland, Local authorities have been required to produce a Short Break Service Statement for some time and there is helpful guidance on the Shared Care Scotland website: <https://www.sharedcarescotland.org.uk/resources/carers-act-overview/making-a-statement-guide-to-developing-a-short-break-services-statement/>

National Short Breaks Information and Guidance Hub

Voice and control are key principles of the Social Services and Wellbeing Act 2014, and information and guidance are essential to realising voice and control in practice. We propose a National Short Breaks Information and Guidance Hub, funded by the Welsh Government, that is accessible to and functional for a wide range of stakeholders, including unpaid carers, people with complex care and support needs, practitioners, commissioners and providers. In addition to offering a searchable directory of break options, the Hub should facilitate conversations about personalised short breaks and help people make connections. Offering *supported choice*, the Hub should:

- Provide guidance, information and inspiration to support practitioners to have meaningful *what matters* conversations relating to short breaks.
- Highlight the wide range of break options (commissioned and non-commissioned) and provide opportunities to explore new break options that are 'outside the box', including community activities that can offer meaningful breaks and peer support.
- Inspire commissioners and providers to think flexibly and creatively about break options.
- Provide a platform for people to think about breaks that align to their interests.
- Offer bespoke advice and assistance, either online or over the telephone.
- Embed a *what matters* approach across all points of contact.
- Collate inspiring short break stories and films that demonstrate the positive impact a break (taken together or apart) can have.

The Hub should also:

- Be accessible in terms of language and format and mindful of diversity.
- Link with other platforms that might be helpful, such as DEWIS Cymru, and with local carer organisations across Wales.

Over-specifying breaks can inhibit creativity (Shared Care Scotland, 2020); hence the Hub should not be prescriptive about break options – a ‘set menu’ of breaks should be avoided.

Shared Care Scotland have published helpful guidance: <https://www.sharedcarescotland.org.uk/publications/good-practice-guide-developing-short-break-bureau/>

The respite offer – a National Respite Initiative for Wales

Respite that connects people with the hospitality, tourism and leisure sectors is well established in several countries, including in the USA and in Scotland. There is compelling evidence of its effectiveness in supporting people to enjoy a personalised short break and in conferring mutual benefits for unpaid carers and the people they support.

There is considerable enthusiasm to develop a National Respite Initiative for Wales, underpinned by funding from the Welsh Government, and there are some emergent examples of good practice. This includes the All Wales Forum *Break from the Routine* project that enables families supporting an individual with a learning disability to experience a meaningful break within their community's hospitality industry: <http://www.forum.allwalesforum.org.uk/break-from-the-routine-respite/>

We propose a social franchise arrangement whereby:

- Local carer organisations (approved delivery partners) engage with local businesses willing to donate a break free of charge and they act as the broker to access a bespoke short break. There is no pressure for the unpaid carer to arrange the break themselves.
- Local carer organisations are supported by national coordination and management arrangements for quality assurance and there is a Memorandum of Understanding.
- There are no costs for carer organisations to sign up.
- The process to donate a break is simple.
- In cases where additional costs are prohibitive, for example transport or food, there are contingency monies to support the break to happen and to ensure parity of access to a break.

The respite offer should explore potential links with local carer recognition and identification schemes across Wales that provide discounted rates for carers or permit free entry to certain venues.

Shared Care Scotland have championed the development of respite in the UK supported by funding from the Scottish Government. There are helpful resources on the Shared Care Scotland website: <https://www.sharedcarescotland.org.uk/respite/about-us/>

National Short Breaks Fund

To ensure people have access to the right break at the right time we recommend a national Short Breaks Fund with sustained long-term funding from the Welsh Government. A national coordinating organisation would be required to manage the fund and to work collaboratively with a delivery partner in each local authority area of Wales. This may be a carers centre or third sector organisation supporting young and adult unpaid carers.

The delivery of micro grant schemes and vouchers have proven successful in Wales, including the award winning NEWCIS *Bridging the Gap* model in North Wales, whereby a managed voucher scheme (unpaid carers are allocated a budget code) supports unpaid carers to access targeted and personalised breaks in a flexible way: <https://drive.google.com/file/d/13cKQgo40hj1omQEslqmgA8rLK4T8Zbaa/view>

Scotland has successfully implemented a Short Breaks Fund for some time. Guidance on the implementation of their

Short Breaks Fund can be found on the Shared Care Scotland website: <https://www.sharedcarescotland.org.uk/shortbreaksfund/>

Looking forward

Additional to the four recommendations, we highlight the importance of:

- **Understanding *what matters* - identifying and evidencing personalised short break needs and intended outcomes.**
- **Capturing *what matters* - outcomes from personalised short breaks.**
- **Commissioning, delivering and scaling up personalised short breaks to reflect *what matters*.**

These priorities for practice development, based on a recently published review of the international evidence (Seddon *et al.*, 2021) and our ongoing work with stakeholders, are key to supporting the delivery of outcome focused breaks to a diverse population and to implementing the four recommendations.

Understanding what matters – identifying and evidencing personalised short break needs and intended outcomes

Understanding what matters to unpaid carers and those they support is key to impactful breaks. This includes the language used to describe break options. Looking at assessment and support planning processes and exploring their effectiveness in capturing and evidencing personalised short break needs and intended outcomes is essential. This work may sit within a wider practice development programme around assessments and support planning as co-produced, creative conversations to:

- Generate shared understanding about *what matters*.
- Facilitate alternative thinking about what works for individuals.
- Encourage positive risk taking that supports the identification of bespoke short break options that might be considered 'outside the box'.
- Promote positive wellbeing outcomes.

Recognising the complexities of negotiating the potentially competing rights, needs and wishes of carers and the people they support, that can sometimes arise when discussing short breaks, will be important.

Capturing what matters – outcomes from short breaks

Capturing and evaluating outcomes from short breaks presents challenges. Key lessons from embedding outcomes in practice in Wales and Scotland are to:

- Move the focus from *attribution* to contribution in considering how different factors might influence an outcome for an unpaid carer.
- Place emphasis on *improving* rather than *proving*.

The *Meaningful and Measurable Action Inquiry Project* (Miller and Barrie, 2016) explores how best to capture and use personal outcomes data, considers the quality of interactions needed to generate robust outcomes data, captures good practice in recording outcomes and highlights the difference made by focusing on outcomes in practice.

A study exploring the utility of a Social Return on Investment Approach to determine the added social value arising from creative breaks is underway. The approach has considerable merit. Researchers at Bangor University are working collaboratively with the Shared Lives organisation to identify what elements of breaks are most important in supporting people to achieve wellbeing outcomes: <http://dsdc.bangor.ac.uk/news/research-into-alternatives-to-day-centre-support-for-people-living-with-dementia-44470>

Commissioning, delivering and scaling up personalised short breaks to reflect what matters

Commissioning for outcomes is essential and it is important to consider:

- The evolving role of commissioners as facilitators of change, bringing together providers, people with complex care needs and unpaid carers to shape future break options.
- The different range of providers and the different means that offer flexibility and choice, including, social prescribing, social enterprises, micro enterprises, care cooperatives, community cooperatives, community-based groups, and the more flexible use of individual and pooled direct payments.

End note

Caring is a voluntary role. In progressing break options, we should ensure that unpaid carers do not feel obliged to provide care; their willingness to provide care and continue in their caring role should not be presumed.

The need to nurture caring communities across Wales is evident and sign up across the Welsh Government portfolios is essential if opportunities for creative short breaks are to flourish.

- How best to establish and sustain links with the foundational economy, including the tourist and hospitality sectors, for example, making links with Visit Wales and UK Hospitality Cymru.
- The digital option and how this can be taken forward post pandemic.
- Cost and no cost options that harness the involvement of local communities – for example, time banking and good neighbour schemes – breaks do not always equate with services and can include activities that are self-sustaining in terms of governance and funding.

“Carers need

To be cared for, too

That’s why we need to know

What matters to you?

No assumptions

Nor painting with

Doom and gloom

We want to feel

The love in this room”

Extract from poem written by carers with Cheryl Beer in an event in the Hi Tide, Porthcawl on 29th September 2017.

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